

Spina Bifida

Also called: Cleft spine, Open spine, myelodysplasia

Spina bifida is the most common disabling birth defect in the United States. It is a type of [neural tube defect](#), which is a problem with the spinal cord or its coverings. It happens if the fetal spinal column doesn't close completely during the first month of pregnancy. This can result in a portion of the spinal cord and the surrounding structures to develop outside, instead of inside, the body.

There is usually nerve damage that causes at least some paralysis of the legs. Many people with spina bifida will need assistive devices such as braces, crutches, or wheelchairs. They may have learning difficulties, urinary and bowel problems, or [hydrocephalus](#), a buildup of fluid in the brain.

Spina bifida is a life-long condition that is not curable. The full extent of the problem is usually not completely understood immediately after birth, but may be revealed as the child grows and develops. Prognosis depends on the number and severity of abnormalities and associated complications. Management of spina bifida often focuses on: the complications, and can include surgery, medicine and physiotherapy; and preventing or minimizing deformities and maximizing the child's capabilities at home and in the community.

Children with spina bifida can lead relatively active lives. Most children with the disorder have normal intelligence and can walk, usually with assistive devices. If learning problems develop, early educational intervention is helpful.

NOTE: This Web page was compiled from a variety of sources including the online resources of Medline Plus, the National Institute of Neurological Disorders and Stroke, St. Louis Children's Hospital and other resources listed below, but is not intended to substitute or replace the professional medical advice you receive from your physician. The content provided here is for informational purposes only, and was not designed to diagnose or treat a health problem or disease. Please consult your health care provider with any questions or concerns you may have regarding this specific condition.

RESOURCES

NOTE: This page contains links to other World Wide Web sites with information about this disorder. Department of Health and Senior Services (DHSS) hopes you find these sites helpful, but please remember the DHSS does not control nor does it necessarily endorse the information presented on these Web sites.

For a complete list of resources related to birth defects, including state programs and resources, support groups and not-for-profit organizations click on the following link

<http://www.dhss.mo.gov/BirthDefects/Resources.pdf>

The Hydrocephalus Association

<http://www.hydroassoc.org/>

Genetic Alliance

<http://www.geneticalliance.org>

March of Dimes

www.marchofdimes.com/

MedLine Plus

<http://www.medlineplus.gov>

National Center on Birth Defects and Developmental Disabilities (NCBDDD)

<http://www.cdc.gov/ncbddd/>

National Institute of Neurological Disorders and Stroke

http://www.ninds.nih.gov/disorders/spina_bifida/detail_spina_bifida.htm

Spina Bifida Association

<http://www.sbaa.org/>

GENETIC TERTIARY CENTERS

How to Obtain Genetic Services

Your family physician can usually provide information regarding genetic services in your area. Genetic clinics are periodically held in a location near you. For information please contact one of the centers listed below.

Genetic Tertiary Centers

[Cardinal Glennon Children's Hospital](#)

St. Louis, Missouri

314-577-5639

[Children's Hospital at University Hospital and Clinics](#)

Columbia, Missouri

573-882-6991

Children's Mercy Hospital

Kansas City, Missouri

816-234-3290

St. Louis Children's Hospital

St. Louis, Missouri

314-454-6093